



Archived at the Flinders Academic Commons:

<http://dspace.flinders.edu.au/dspace/>

This is the authors' version of an article accepted for publication in the journal *Child Language Teaching and Therapy*. The original is available by subscription at:

<http://clt.sagepub.com/content/30/2/141.abstract>

Please cite this article as:

Grace, E., Raghavendra, P., Newman, L., Wood, D., and Connell, T., 2014. Learning to use the Internet and online social media: What is the effectiveness of home-based intervention for youth with complex communication needs? *Child Language Teaching and Therapy*, 30(2), 141-157.

DOI: doi: 10.1177/0265659013518565

© 2014 The Authors

**Please note** that any alterations made during the publishing process may not appear in this version.

This is the Author Post-Print version, incorporating reviewer comments, of the paper published as:  
Grace, E., Raghavendra, P., Newman, L., Wood, D., & Connell, T. (2014). Learning to use the Internet and  
online social media: What is the effectiveness of home-based intervention for youth with complex  
communication needs? *Child Language Teaching and Therapy*, 30 (141 - 157).

## **Learning to use the Internet and online social media: What is the effectiveness of home-based intervention for youth with complex communication needs?**

### **Abstract**

Youth with complex communication needs (CCN) face increased barriers to their social participation due to limited communication abilities and opportunities. Youth today use the Internet as a social tool and youth with CCN may also benefit from Internet use to increase their social participation. Five youth between the ages of 10-18 with CCN who are unable to use speech for everyday communication and require augmentative and alternative communication were provided with assistive technology and a tailored 1:1 intervention at home to learn to use the Internet for connecting with others. Pre and post assessments measured changes in performance on Internet use goals, social networks, loneliness and self-concept. Multiple measures were used to examine the impact of Internet use for social networking on a range of outcomes and to gather emerging evidence in this area. Results showed that the intervention was effective in increasing performance and satisfaction with goals for increasing Internet use to connect with others and for increasing the number of online communication partners. There was no significant change in loneliness or self-concept. This study shows that the Internet may be a viable tool in increasing the social participation of youth with CCN. However, some youth and their families required intensive support and technical assistance to gain confidence in Internet use and in use for social purposes.

### **Keywords**

**Youth, complex communication needs, social media, intervention, social networks**

## Introduction

Social participation is important for youth health and well-being, in developing and maintaining friendships and contributing to a sense of belonging. Recent research suggests the importance of social participation as a focus of health-based interventions, including via the Internet (Corsano et al., 2006; Eriksson et al., 2012; Nansen et al., 2012). Individuals with complex communication needs (CCN) are unable to use speech for everyday communication and may benefit from augmentative and alternative communication (AAC). People with CCN who rely on AAC have atypical communication patterns including reduced rate of message transfer, increased passive role, reduced initiations, and limited opportunities for interactions that impact on participation (Blackstone and Hunt Berg, 2012).

Children and adolescents with CCN have reduced social participation. Their social networks are mainly limited to family members and paid workers such as teachers and therapists, with fewer acquaintances and friends compared to typically developing peers (Raghavendra et al., 2012a; Thirumanickam et al., 2011). This highlights the necessity of communication for social participation (Batorowicz et al., 2006). Young adults with CCN (aged 24-30, Cooper et al., 2009) and older adults aged 40-69 (Balandin et al., 2006) may also be at higher risk of loneliness. This research highlights the urgent need to address the issues of reduced social networks and loneliness in individuals with CCN across the lifespan.

### *Youth without disabilities- social contact via the Internet*

The use of Internet technology for social networking is a pervading feature of youth culture today, with social and recreational online media used as much and as often as possible (Ito et al., 2008). In Australia, social networking sites are regularly used by teenagers, with 90% of 12-17 year olds and 97% of 16-17 year olds reporting regular use (ACMA, 2009). A large body of research focuses on these technologies and the effects on youth, with the impact of social networking sites on youth's self-esteem and psychological well-being a particular focus (Ahn, 2011). Harter (1999) argued that social relationships contribute significantly to the development of self-concept. A recent study proposes that positive social relationships such as mentoring relationships between adolescents are a significant factor in the development of self-esteem (Schwartz et al, 2012).

A review of studies in Japan (Takahira et al., 2012) found that in youth aged 10-18, Internet usage had both positive and negative effects on learning and social adjustment. For example more internet use in high school students had been shown to lead to increased tendency to talk about themselves, enhancing intimacy and improving mental health. Young people who used the internet frequently had increased support and help from others enhancing their social adjustment. However, the authors also reported that several studies found negative effects on mental health and suggested that in addition to education about the dangers of using the internet, young people should also receive education targeting more basic communication abilities such as social skills and other factors not specific to internet use and this might may buffer against the potential negative aspects of internet use. A study by Valkenburg and Peter (2007) found a positive relationship between internet use and well-being amongst Dutch teenagers (10-17 year olds). Survey results demonstrated that young people mostly talked online with friends they also knew offline, potentially strengthening the quality of existing relationships and perhaps acting as a mechanism to enhance well-being (Valkenburg et al., 2007). However, while younger people have high ICT use overall, not all youth are online and even those with Internet access can face barriers to successful use (Hargittai, 2010).

### *Youth with disabilities -social contact via Internet, and wellbeing*

Some studies have focused on how youth with disabilities use the Internet for social connection. An exploratory study investigated Internet use, loneliness and self-esteem in hearing impaired adolescents (Barak and Sodovsky, 2008). The hearing impaired adolescents with lesser Internet use felt lonelier and had lower self-esteem than the hearing impaired participants with more Internet use. A Dutch study found that 99% of youth aged 13-18 years with physical disabilities had Internet access and reported similar use and access patterns to their typically developing peers (Lathouwers et al., 2009). In a pilot study we conducted a survey and interviews to identify enablers and barriers to Internet use among 10-18 year olds with physical disabilities or acquired brain injury (Newman et al., 2010; Raghavendra et al., 2011; Raghavendra et al., 2012b). Although the response rate was low (21% and 29.5%), among those who did return the forms 95% used the Internet and a key facilitator was support from siblings and friends. An online peer support intervention study with 22 adolescents with cerebral palsy (CP) or spina bifida over a 6-month period investigated loneliness and self-perceptions before and after intervention. Participants felt the intervention helped them to learn new information, meet others with a disability and make new friends (Barnfather et al., 2011).

Individuals who use AAC “have a need for, and a right to, the same range of communication options available to everyone else” (RERC on Communication Enhancement, 2011: p.3). Social media and online social networking provide a new opportunity for youth with CCN to communicate without time pressure and prejudice (Barnfather et al., 2011; Raghavendra et al., 2012b). Currently, no research has specifically investigated the effectiveness of training on Internet use and online social networking and its impact on the social networks and wellbeing of youth with CCN. This paper reports the effectiveness of a home intervention on Internet and social media use and the impact on the loneliness, self-concept, and social networks among youth with CCN.

## **Method**

The study was approved by the Children, Youth and Women’s Health Services Human Research Ethics Committee. This study used a single group pre-post design comparing quantitative data from five youth with CCN who were part of a larger sequential mixed-methods study (Raghavendra et al., 2013a). Participants had individualised intervention goals and therefore a pre-post design was considered the most appropriate, where each participant was their own control.

### *Participants*

Participants were clients of Novita Children’s Services Inc., an organisation providing services for children with physical disabilities or acquired brain injury in the state of South Australia. Participants met the following criteria: diagnosed with a physical disability such as cerebral palsy (CP), other physical condition or acquired brain injury; aged 10–18; residing in Adelaide (the state’s capital city). Participants who were at a pre-intentional level of communication were excluded. The study was advertised to Novita staff and clients. The young person, a parent, or a professional responded to indicate the need for the young person to learn to use, or learn more about using, the Internet for social networking. Eligible participants were invited to the study (n=123) and 18 agreed to participate. From this larger group, five were identified as having CCN using a range of AAC systems. Table 1 presents demographic information on the participants. The mean age was 13;3 years. Table 1 includes information on the participant’s gross motor and hand function as reported on the Gross Motor Function Classification System (GMFCS, Palisano et al., 2008) and Manual Ability Classification System (MACS, Eliasson et al., 2006). Three participants were at Level I or II on GMFCS and MACS showing milder

physical disabilities, whereas two participants on Level IV or V on GMFCS and MACS were youth with severe limitations in head, trunk and hand control, requiring extensive assistive technology and total assistance; mobility was only through powered wheelchair. Participants' communication abilities were classified using the Communication Function Classification System (CFCS) designed for individuals with CP and other disabilities (Hidecker et al., 2011). Communication abilities are described at five function levels according to the effectiveness of sending and receiving messages with familiar and unfamiliar partners. Participants on CFCS Level III are effective senders and receivers with familiar partners, where as those on Level V are seldom effective senders and receivers with familiar partners (Hidecker et al., 2011). Four of the five participants used complex technology to support their communication needs, with three using direct access (i.e., touch screen) and one using two-switch scanning.

**Table 1. Participants' demographic and ability characteristics.**

Person	Age	Sex	Diagnosis	AAC systems	CFCS level *	GMFCS level **	MACS level ***	Class type	School level
1	10;6	M	Other Physical Disability	PODD™ ^	III	I	I	Mainstream	Primary
2	15;6	F	Other Physical Disability	iPad™, iPhone™, Proloquo2go™	III	I	I	Special class	High
3	14;3	M	Cerebral Palsy	PODD™ Dynavox Maestro™,	IV	IV	IV	Special class	High
4	13;7	F	Other Physical Disability	PODD™ Dynavox V™, iPad, Proloquo2go™	III	II	II	Special class	High
5	12;3	M	Cerebral Palsy	Tobii™ C12, Grid2™: Word Power™	V	V	V	Special class	Primary

\*CFCS: Communication Function Classification System (Hidecker,2011)

\*\*GMFCS: Gross Motor Function Classification System (Palisano et al, 2008)

\*\*\*MACS: Manual Ability Classification System (Eliasson et al, 2006)

^PODD: Pragmatically Organised Dynamic Display (Porter, 2007) Communication Book

### *Measures and procedure*

The following measures were administered before and after the intervention. Participants were interviewed together with their parent using the Canadian Occupational Performance Measure (COPM, Law et al., 1998), a semi-structured interview tool to identify problems in using the Internet for social networking. Once problem areas had been identified, participants then rated their performance level and satisfaction with their performance for each problem on a 1-10 point scale (1 = not able to do it, not satisfied at all; and 10 = able to do it extremely well, extremely satisfied). Participants were asked to show the research assistant how they used the Internet. Strengths and challenges were informally observed and noted by the research assistant (e.g., physical access or literacy barriers). Literacy level was not measured formally. The Goal Attainment Scaling (GAS, Kiresuk and Sherman, 1968) was then used to develop between 1-3 goals per participant. GAS is used to set and measure goals on a 5 point scale ranging from -2 (current performance) through to +2 (well above expected performance). For example, goals included increasing independence in reading online text, writing and sending an email, or making a Skype video call.

Information on participants' communication partners was gathered using the Circles of Communication Partners (CCP) tool, a section of the 'Social Networks: A communication Inventory for individuals with CCN and their communication partners' (Blackstone and Hunt Berg, 2012). This gathers information about the variety of communication partners and context of communication and social participation. The five circles are:

- Circle 1: life-long communication partners (e.g. immediate family, close relatives)
- Circle 2: close friends and extended family members.
- Circle 3: acquaintances (e.g. classmates).
- Circle 4: paid worker (e.g. teachers, doctors).
- Circle 5: people that we interact with but don't know (e.g. people at shops).

Given this study's focus, a sixth circle was developed to record and describe online communication partners (Raghavendra et al., in press b). Even though the need for Circle 6 can be questioned as the above five circles cover all online and off line communication partners, it was included as the study focus was on online communication and the impact of intervention on it. The partners in the five circles were first recorded. Then



participants were asked whether they communicated with anyone using email, Skype, Facebook or other social media. Each partner in Circle 6 was later identified by the research officer as belonging to other Circles.

Feelings of loneliness were measured using the Asher Loneliness and Social Dissatisfaction Questionnaire Scale (ALSDQ, Asher et al., 1984). This includes 16 target items (e.g. "I can find a friend when I need one") and 8 filler items (e.g. I like science) self-rated on a 5 point Likert scale (1 = Not true at all, 5 = Always true). Possible scores range from 16-80, with larger scores indicating greater loneliness and social dissatisfaction.

Self-concept was measured using the Beck Youth Self-concept Inventory (B-SCI, Beck et al., 2005). Participants respond on a 4 point Likert scale (Never, Sometimes, Often, Always) to 20 statements about themselves (e.g. "I work hard"). Scores were calculated and converted into T scores as described in the inventory manual. The B-SCI and ALSAQ scales were used in consideration of the language demands of the measures and suitability for participants across the age range in the study. The tools have been shown to be reliable and valid (Asher et al., 1984; Beck et al., 2005).

The COPM, ALSAQ, B-SCI and CCP measures were completed before intervention by the participants together with the research officer. Participants were trained in each rating scale prior to use and supported to provide a non-verbal response

### *Intervention programme*

The intervention programme included provision of technological solutions, support, and training to overcome opportunity and access barriers to Internet access/use. It was conducted in each participant's home and sessions included training on and providing guidelines specific to the participant's cyber safety needs, goals and abilities. Strategies and supports provided to participants and their families included developing a cueing hierarchy to support the family member in guiding the participant to learn with increasing independence to access email via a speech generating device using scanning; use of visual prompts for steps to using Skype; and help cards to support use of a screen reading and word prediction program. Participants and families received prompt and responsive troubleshooting support and technical training to increase success in the initial stages of introducing the new technology (e.g. connecting a complex communication device to the Internet, setting up email and programming changes to communication pages). Support was also provided by phone between

visits. Participants were allowed to keep the assistive technology, hardware and/or software after the project so that they could continue using the Internet and social media. Assessment measures were repeated between 4 days and 2 weeks after the completion of the intervention.

### *Data analysis*

Results were analysed for all six measures: COPM performance, COPM satisfaction with performance, GAS, B-SCI, ALSDQ and CCP. Participants' mean COPM pre and post ratings for performance and satisfaction with performance, ALSDQ raw score and B-SCI T score were analysed using the paired T-test. While we recognise that meeting parametric test assumptions for a small sample size may bring about problems, we decided to utilise them as for some measures the raw scores demonstrated a clinically significant change following intervention. Furthermore other researchers in our field with smaller sample sizes utilised the same statistical tests (Ostensjo et al., 2008; Cusick, 2006). To address this limitation, we have reported confidence intervals obtained through bias corrected accelerated (BCa) bootstrapping, which we acknowledge also have limitations on their own (Cirincione & Gurrieri, 1997; Wood, 2005). Changes in CCP before and after intervention were analysed using the Wilcoxon Signed Ranks test given approaches for analysing count data do not use parametric statistics as this data theoretically should not be normally distributed. The GAS values were converted to T-scores using the formula developed by Kiresuck and Sherman (1968) and demonstrated by Turner-stokes (2009).

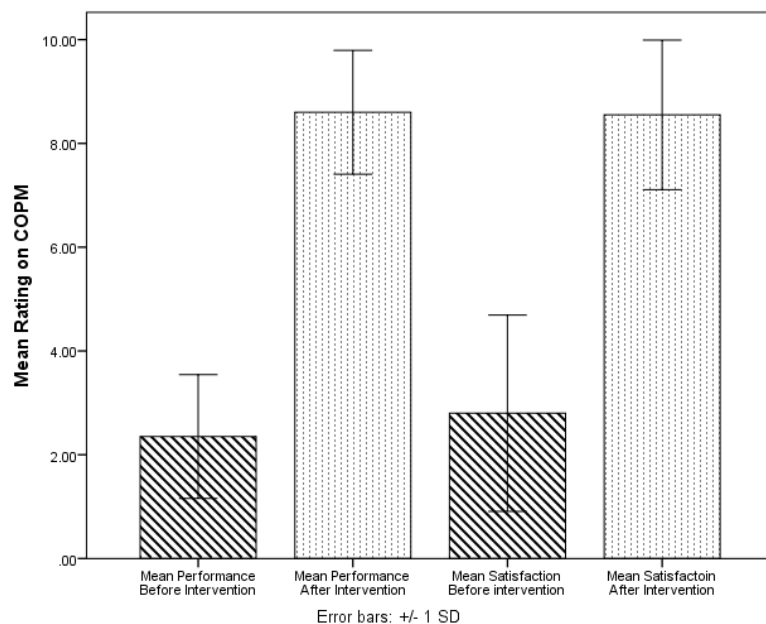
## **Results**

Intervention extended over a mean period of 6.9 months (SD = 3.44). Each participant received a mean of 12.8 visits (SD= 2.5) lasting an average 74.6 minutes/visit (SD=11.8). In addition, the research officer and assistant spent a significant amount of time to prepare and develop visual resources, program and troubleshoot complex speech generating devices used for online social networking, and travel to participants' homes.

### *Canadian Occupational Performance Measure*

Using the COPM, a total of 10 problem areas were identified for the five participants (range 1-4, mean =2.0). Problems related to a lack of knowledge and skills regarding use of social networking platforms (e.g. how to use email or make Skype calls) and/or to increasing a participant's independence in computer use (e.g. support

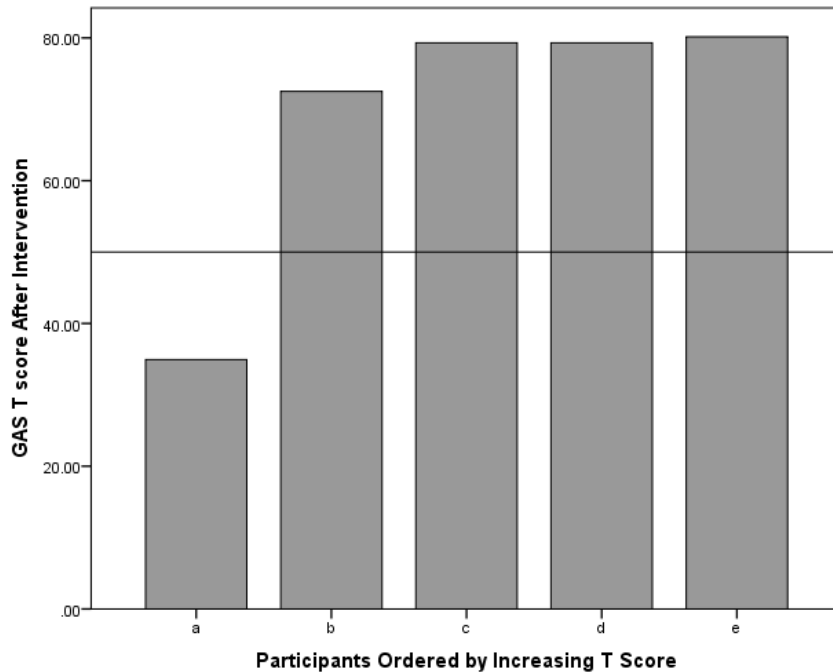
to write email, read email or to be safe online). Scores rated by participants on a 1-10 scale showed gains in performance, and satisfaction with performance, as shown in Figure 1. All participants on all problem areas rated increased performance and satisfaction following intervention. The mean performance score increased from 2.35 (SD = 1.19) to 8.60 (SD = 1.19), and the mean satisfaction with performance score increased from 2.80 (SD=1.89) to 8.55 (SD =1.44). Authors of COPM state that a change in score of two or more points demonstrates clinically significant change (Law et al., 1998). The paired T-test showed that both were statistically significant  $t(df=4) = -6.93, p > 0.002$ , Bca 95% CI [-7.8, -4.7],  $d = 2.96$  and  $t(df=4) = -6.64, p > 0.003$ , Bca 95% CI [-7.5, -4.5],  $d = 1.93$ . Changes in COPM rated performance and satisfaction demonstrate a statistically and clinically significant change following intervention.



**Figure 1. Mean COPM ratings before and after intervention.**

### *Goal Attainment Scale*

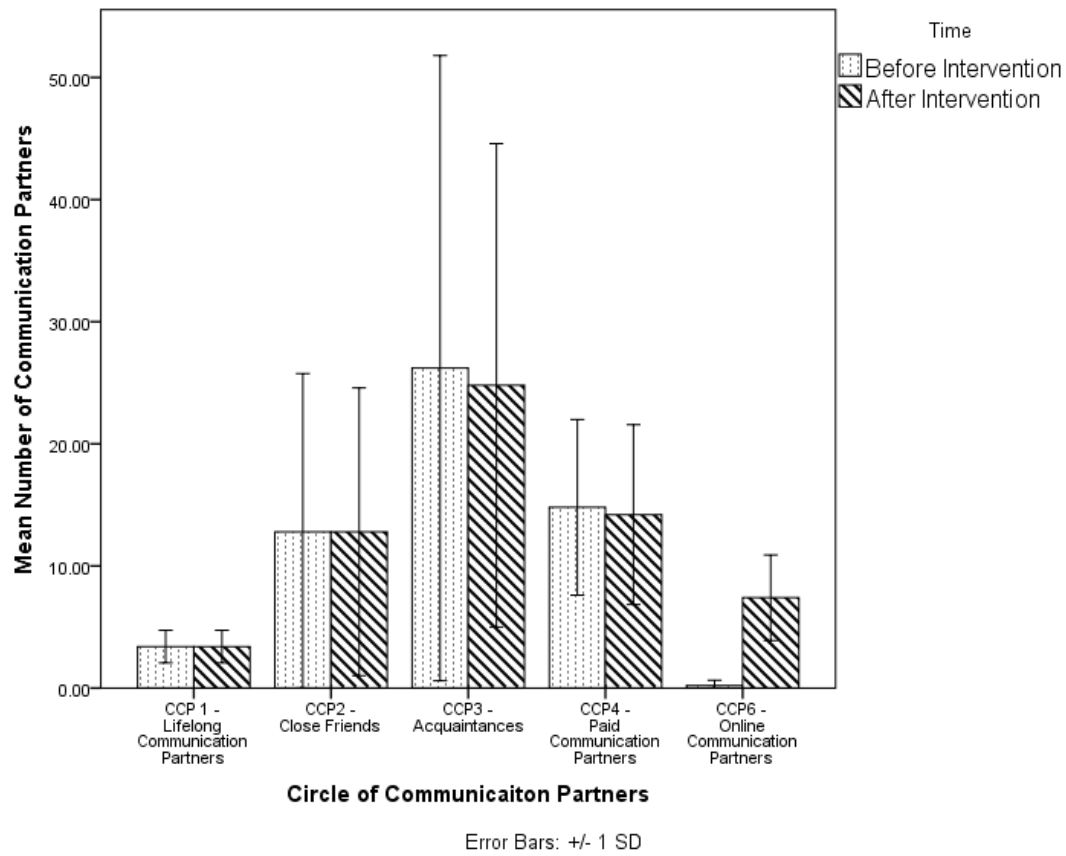
Nine of the 11 goals were attained or exceeded at post intervention (82%). All goals were achieved or exceeded by four out of five participants. However, one participant's goals were not met to the expected level as shown in Figure 2. Since the number of goals varied across participants (range 1-3, mean = 2.2) T-scores were calculated to provide a summary score of aggregated goal achievement. A T-score of 50 indicates that goals were achieved as expected. The mean T-score across participants was 69.2 (SD = 19.4).



**Figure 2. GAS T scores by participant after intervention.**

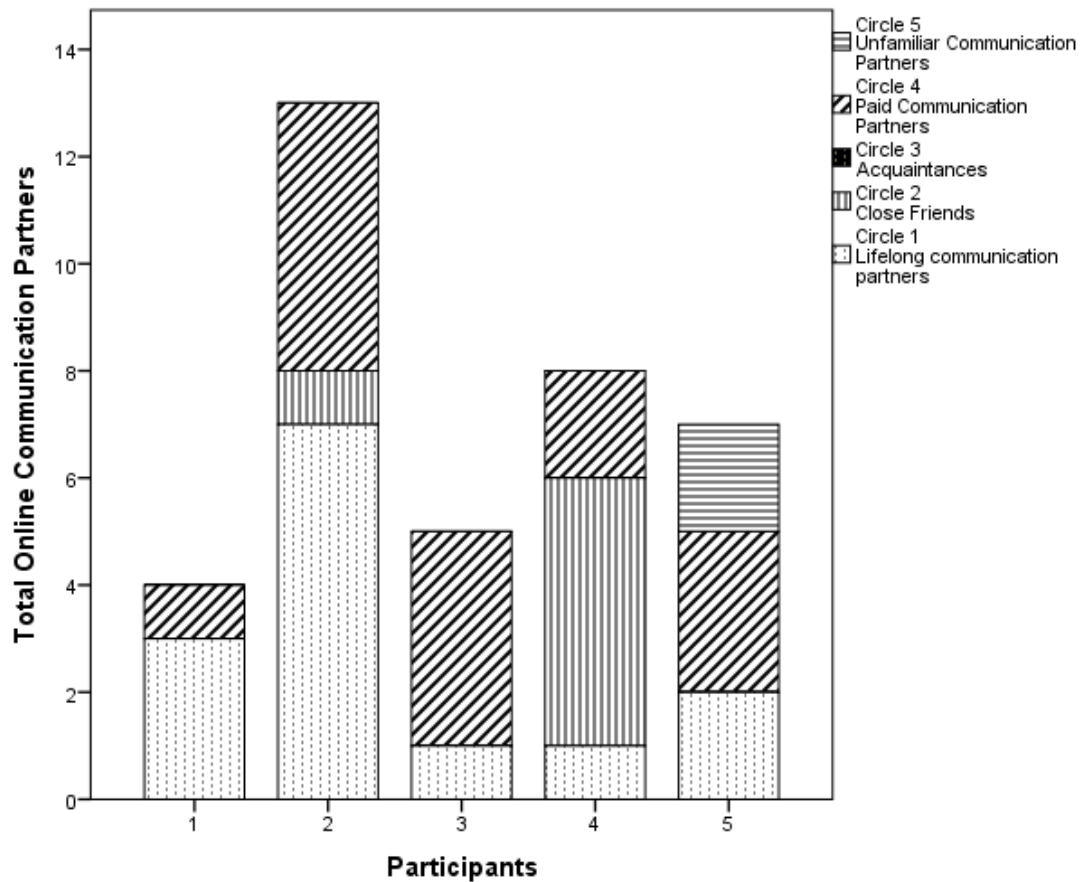
### *Impact on social networks*

Figure 3 shows the mean number of communication partners identified in each circle before and after intervention. Mean numbers for Circle 5 (unfamiliar partners) were not calculated because participants found it difficult to list the number of partners. Instead they listed places such as shopping centres or hospital, where they interact with groups of people rather than individuals. The standard deviations for Circle 2 (good friends), Circle 3 (friends and acquaintances) and Circle 4 (paid communication partners) were higher, indicating variation among the group. The number of communication partners reported in Circles 1-4 was similar before and after intervention and Wilcoxon signed ranks test showed that differences were not statistically significant (Circle 1,  $p=1.0$ ,  $d=0.00$ ; Circle 2,  $p=1.0$ ,  $d=0.00$ ; Circle 3,  $p=.854$ ,  $d=0.03$ ; Circle 4,  $p=.083$ ,  $d=0.05$ ). Before intervention, only one participant reported Internet use, and they communicated with a family member. Following intervention, participants reported a mean of 7.4 (SD =3.5, Range =4-13) online communication partners. The increase in online partners was statistically significant with the Wilcoxon signed ranks test (Circle 6,  $p > 0.043$ ,  $d=1.63$ ). Figure 4 shows that online communication partners reported by participants post intervention were largely family members (Circle 1) and paid partners (Circle 4).



**Figure 3. Mean number of Circles of Communication partners before and after intervention.**

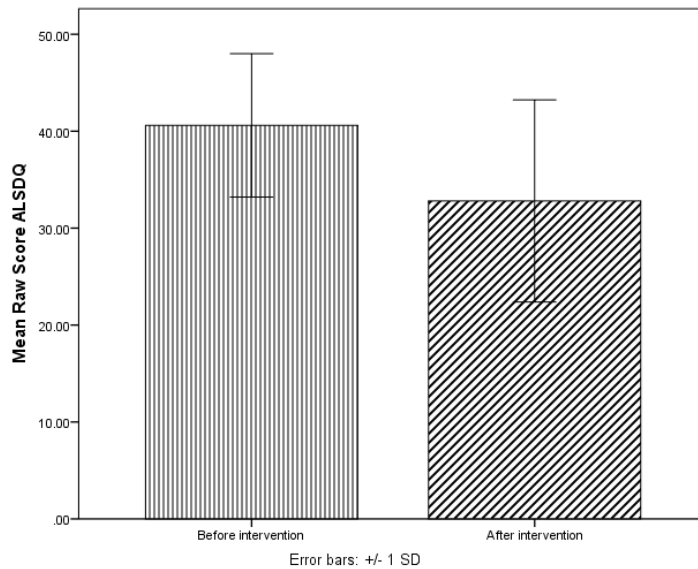
Note. excludes Circle 5 as mean number not calculated



**Figure 4. Post-intervention online communication partners from Circles 1 to 5.**

### *Asher Loneliness and Social Dissatisfaction*

The ALSDQ raw scores ranged from 32-52 before intervention and 20-48 after intervention. In the original normative sample (Asher et al. 1984), scores ranged from 16-79 with a mean score of 32.51 (SD 11.82). The mean score in this study was 40.6 (SD = 7.4) before intervention and 32.8 (SD = 10.43) after intervention. One participant in this study reported feelings of greater loneliness (>44.3, 1SD above the mean for the normative sample) before and after intervention. The paired T test showed that the difference between the mean loneliness before and after scores was not statistically significant,  $t(df = 4) = 2.14$ ,  $p = 0.099$ , Bca 95% CI [2.8, 13.4],  $d = 0.49$ . On 14 out of 16 items, the mean ratings decreased, indicating that there was a decrease in measure of loneliness.



**Figure 5. ALSDQ Mean raw score before and after intervention.**

### *Beck Self-concept Inventory*

T scores on the B-SCI ranged from 42-65 before intervention and 45-55 after intervention. According to the Beck et al., (2005), T scores between 45-55 are considered as having average self-concept. Higher scores demonstrate increased self-concept. The mean score before intervention 51.8 (SD =8.44) was within the average range and comparable to the mean score after intervention 50.0 (SD =4.53). The paired T –test showed that this difference was not statistically significant,  $t(df=4) = -0.64, p=0.555$ , Bca 95% CI [-2.8, -7.0],  $d=0.15$ .

### *Case Study Example*

A case example illustrates the intervention’s nature and outcomes.

Kelly (pseudo name) is a 15.6 year old girl with other physical disability (Participant 2 in Table 1). Kelly has no natural speech and uses signing and gestures primarily for communication as well as iPad™<sup>1</sup> with Proloquo2go™<sup>2</sup>. When she was away from home (e.g. respite or hospital stays) less familiar staff found it difficult to interpret Kelly’s communication attempts. She had access to word prediction on her iPad™ within the communication application (Proloquo2go™), but did not have word prediction support on the home computer. She had difficulty reading online text as her literacy skills were poor. Using the COPM, problem

areas were identified with Kelly and a parent, and scored for performance and satisfaction with that performance, as per Table 2 below.

Given her poor literacy skills, Kelly was provided with Word Q™<sup>3</sup> and Speak Q™<sup>4</sup> software to support her online reading and writing. Kelly's parents were particularly concerned regarding cyber safety and felt that Kelly was unaware of potential dangers and may unintentionally write inappropriate messages online due to her poor literacy and communication skills. Although Kelly would have liked to have learned to use more popular social networking sites (e.g., Facebook, Twitter), due to the concern for her safety, we connected her only to trusted communication partners via Skype. When Kelly was away from home with less familiar communication partners (e.g., in hospital), Skype enabled her to call a more familiar communication partner and the video support reduced communication breakdown and increased understanding of Kelly's signs. When using Skype with partners who did not understand her signing clearly, Kelly used instant messaging to communicate her message. A major benefit for Kelly was reduced isolation when in hospital as she could connect with her family, increased success in repairing communication breakdown with the hospital staff. She was also able to connect with other family members using Skype and email, which she had not previously been able to do.

Kelly received 12 intervention sessions over an 8.5 month period, with a mean duration of 66 minutes. During this time, screen reading software, word prediction software, Skype and an Internet filter were installed on the home computer and a laptop. However, several technical difficulties with these installations extended support time. For example, Kelly's family were unfamiliar with some computer password locks, their computer required updated scanning and virus protection, and their web camera compatibility and microphone needed checking. A laptop on loan and one month paid Internet connection were provided to facilitate use in other settings. Kelly was provided with training and discussion of cyber safety rules that were repeated at each appointment, and a visual support was developed for each rule and provided to Kelly. She was supported to learn basic operating skills for Speak Q™ and Word Q™ and use of email (Gmail) and Skype. Prior to intervention, Kelly's one online communication partner was from Circle 1 (life-long partners). Following intervention, Kelly had 13 online communication partners from Circles 1, 2 (good friends) and 4 (paid communication partners), the highest amongst the participants.



Her mean COPM performance score increased from 4.25 to 8.5 and satisfaction score from 5 to 9.25. Her self-concept T score on B-SCI remained relatively stable increasing slightly from 42 to 46 (ratings on individual items demonstrated an increase in self-concept for 8 /20 items). Her loneliness score decreased from 42 to 35. On 50% of items on the ALSDQ, Kelly rated a decrease in loneliness after intervention compared to before intervention. Kelly reported that the project was “great”, “useful” and “excellent” and was able to communicate more to family, friends, teachers and staff.

**Table 2. Kelly’s COPM ratings before and after intervention.**

Goals	Performance	Satisfaction	Performance	Satisfaction
	before	before	after	after
	intervention	intervention	intervention	intervention
Reading the screen	7	5	8	9
Writing emails	4	7	6	8
Safety online	5	3	10	10
Learn to make Skype calls	1	5	10	10

## Discussion

This paper details the effectiveness of a tailored one-on-one intervention using Internet social networking and social media to increase the social participation and communication of youth with CCN. Support and training were effective in increasing Internet use for connecting with others, as demonstrated by significant increases in mean performance and satisfaction with that performance on the COPM, and by the level of mean goal achievement on the GAS. Increases in performance and satisfaction with performance were observed in all five participants regardless of level of physical disability (e.g., GMFCS level). Even the participant at Level V GMFCS and MACS showed increases in performance and satisfaction with performance.

There was a significant increase in the mean number of online communication partners following intervention. However, this needs to be interpreted with caution as there was floor effect in the number of online communication partners before intervention. Furthermore, online communication partners were mainly from Circle 1 (immediate family members) and Circle 4 (paid communication partners). Two participants also

communicated online with relatives and close friends following the intervention (Circle 2). There is therefore room to investigate the interactions between offline friendships of youth with CCN and the extent to which this offers potential for new or extended communication online. Even though the online partners were subsumed into other circles, further research can investigate whether online communications do open up a medium for the formation of relationships that are quite distinctly different from the relationship in face to face situations. Although we hypothesised that there would be increases in the numbers in Circles 2 and 3 (close friends and acquaintances) after intervention, the numbers did not change. It must also be pointed out that we did not measure quality or frequency of interactions which may have changed while the mean number of CCPs did not. The study's short time frame and time taken to address technological challenges may have been influential. Future research could target interventions to increase communication partners in Circles 2 and 3 by pairing peers or acquaintances who may not communicate with young people with disabilities offline to support both groups to interact online. These conclusions agree with Takahira and colleagues (2012) who recommended enhancing support for basic communication and social skills and the inclusion of longitudinal data in future studies.

Friendship development is a subtle process requiring a series of connection experiences (reciprocal expression of positive emotions) in a limited time period (e.g., a few months –a 'bonding phase'), followed by an offer and acceptance of a friendly gesture (e.g., invitation or help etc) which may be followed by a 'maintenance phase.' This latter phase can involve simpler, less frequent, reciprocal communication, but with at least some degree of emotional reciprocity for the friendship to be kept alive. Whether all these types of interactions can occur within on-line communications and whether it is possible to teach parts of the process is an important question for further research.

The study found a reduction in mean loneliness scores, from 40.6 to 32.8, indicating that changes were in a positive direction although not statistically significant. A similar pattern was seen after intervention in the larger study of youth without CCN (Raghavendra et al., 2013b). There is little research using the ALSDQ in youth with disabilities and these five participants did not have high levels of loneliness to begin with. Stewart et al's (2011) study using online peer mentoring with youth with CP and Spina Bifida did not show significant difference and authors commented that it was not sensitive to change over this time period. Loneliness is a complex construct that may require longer time and different strategies to see changes, or may not be

reduced simply by increasing the number of friends. Self-concept was in the average range for these participants at the intervention's start and stayed at a similar level after intervention. The self-concept and loneliness measures showed that there were no adverse changes following intervention. The lack of significant change could be due to measures taken after three to six months, whereas these concepts may take longer time to show changes and to further establish and expand online friendships. The small sample size may also be another factor.

Study benefits varied across individuals, with one participant not achieving expected results on the GAS by the end of the intervention. The participant's goals were to write an email and send it independently and to use software to support reading the screen. The participant was able to do the above with one-to-one support but not independently; this level of attainment might have been difficult within the time frame of the project. This participant and family would have benefited from increased and ongoing support in computer and Internet access, since the participant had been using a computer at school prior to the intervention, but had used neither computer nor Internet at home. Families and participants varied in their background knowledge and confidence in computer and Internet use and often required individualised, and in some cases specific strategies, to support introduction to, and successful use of, these technologies.

Technological difficulties were a significant issue for this group. Participants and families faced significant technical barriers, requiring contact between the research officer, suppliers of assistive technology, online forums and IT specialists over several weeks to resolve issues. Despite living in a metropolitan area, some also had difficulty in establishing a reliable Internet connection at home and across environments, and encountered hardware and software problems. For example, in one case, the wireless adaptor provided with the communication device could not support the home wireless signal and an external wireless adaptor had to be purchased to provide a home connection. AAC devices must provide easy access to online connections so that youth with CCN can connect with social media. Disability service providers need to consider access to IT consultant support, and staff time required to teach or support Internet use. Families required support for programming symbol grids to support email access as changes were required to pre-made page sets on speech generating device. These technical difficulties could not be addressed by these participants or families alone, and the intervention support was necessary to establish connections and setup the technology.

One limitation of this study is the small number of five participants and limited range of social media used. Our participants varied in their physical and communication disabilities and required varying levels of intervention. All participants were observed to have poor basic literacy skills (writing, reading and comprehension of text). Although this was not initially a planned focus of intervention and not formally measured it became obvious that the participants had challenges in this area. Individual supports were required to scaffold their success in accessing Internet social media which are mainly designed for individuals with good literacy skills. Future research should consider including formal measures of literacy. Even the participant at Level V of GMFCS, MACS and CFCS showed positive outcomes in all areas, but this was only achieved with intensive support and training. Our study shows benefits of social media and online social networking for youth with CCN, but also showed that specialist disability and IT expertise is required to support this.

## **Conclusions**

The outcomes from this study showed that the five youth with CCN who also had significant physical and communication difficulties learnt to write and read emails, communicate over Skype, and be safe online. The performance on these goal areas and satisfaction with performance increased significantly after intervention. With almost no online communication partners at the study's commencement, the number increased significantly after intervention with members predominantly from Circles 1 and 4. The study's limitation was the small sample size with varying abilities. Identifying specific steps in the vital, but subtle process of friendship development, their individual importance to a young person's social experience, and how much they can occur on-line and be taught, are vital areas for future research. It is also important to extend the study outcomes to a larger group of individuals with CCN, and to conduct longitudinal follow-up, and investigate if online social networks can be extended to friends and acquaintances over longer time periods.

## **Funding**

This study was funded by the Channel 7 Children's Research Foundation of South Australia [grant number 11426, 2010].

## Notes.

1. PODD Pragmatic Organisation Dynamic Display is a registered trademark of Gayle Porter
2. iPad is a registered trademark of Apple Inc.
3. Dynavox Maestro is a registered trademark of Dynavox Systems LLC.
4. Dynavox V is a registered trademark of Dynavox Systems LLC.
5. Tobii is a registered trademark of Tobii Technology Inc.
6. Grid2 is a product of Sensory Software International Ltd, 4a Court Road, Malvern, Worcestershire, WR14 3BL, UK.
7. Word Power is a product of Sensory Software International Ltd, 4a Court Road, Malvern, Worcestershire, WR14 3BL, UK

## Conflict of Interest Statement

The Authors declare that there is no conflict of interest.

## References

- ACMA. (2009) *Click and Connect: Young Australians' Use of Online Social Media, 02: Quantitative Research Report*. Canberra, Australia.
- Ahn J. (2011) The effect of social network sites on adolescents' social and academic development: Current theories and controversies. *Journal of the American Society for Information Science and Technology* 62: 1435-1445.
- Asher SR, Hymel S and Renshaw PD. (1984) Loneliness in children. *Child Development* 55: 1456-1464.
- Balandin S, Berg N and Waller A. (2006) Assessing the loneliness of older people with cerebral palsy. *Disability and Rehabilitation* 28: 469-479.
- Barak A and Sodovsky Y. (2008) Internet use and personal empowerment of hearing-impaired adolescents. *Computers in Human Behaviour* 24: 1802-1815.
- Barnfather A, Stewart M, Magill-Evans J, et al. (2011) Computer-mediated support for adolescents with cerebral palsy or spina bifida. *Computers, Informatics, Nursing: CIN* 29: 24-33.
- Batorowicz B, Mcdougall S and Shepherd TA. (2006) AAC and community partnerships: The participation path to community inclusion. *Augmentative and Alternative Communication* 22: 178-195.
- Beck JS, Beck AT, Jolly JB, et al. (2005) *Beck Youth Inventories: Second Edition for Children and Adolescents*: Psychological Corporation.
- Blackstone S and Hunt Berg M. (2012) *Social Networks: A Communication Inventory for Individuals with Complex Communication Needs and their Communication Partners*, Wisconsin, USA: Attainment Company.
- Cooper L, Balandin S and Trembath D. (2009) The loneliness experiences of young adults with cerebral palsy who use augmentative and alternative communication. *Augmentative and Alternative Communication* 25: 154-164.
- Corsano P, Majorano M and Champretavy L. (2006) Psychological well-being in adolescence: the contribution of interpersonal relations and experience of being alone. *Adolescence* 41: 341-353.
- Cusick M, Novak I, Lannin, et al. (2006) A comparison of goal attainment scaling and the canadian occupational performance measure for paediatric rehabilitation research. *Pediatric Rehabilitation* 9: 149-157.

- Eliasson A, Krumlinde-Sundholm L, Rosblad B, et al. (2006) The Manual Ability Classification System (MACS) for children with cerebral palsy: scale development and evidence of validity and reliability. *Developmental Medicine & Child Neurology* 48: 549-554.
- Eriksson U, Hochwälder J, Carlsund Å, et al. (2012) Health outcomes among Swedish children: the role of social capital in the family, school and neighbourhood. *Acta Paediatrica* 101: 513-517.
- Hargittai E. (2010) Digital Na(t)ives? Variation in Internet skills and uses among members of the "Net Generation". *Sociological Inquiry* 80: 92-113.
- Harter S. (1999) The construction of the self: A developmental perspective. NY: The Guilford Press.
- Hidecker MJ, Paneth N, Rosenbaum PL, et al. (2011) Developing and validating the Communication Function Classification System for individuals with cerebral palsy. *Developmental Medicine & Child Neurology* 53: 704-710.
- Ito M, Horst H, Bittanti M, et al. (2008) Living and Learning with New Media: Summary of Findings from the Digital youth Project. *The John D and Catherine T MacArthur Foundation Reports on Digital Media and Learning*. Cambridge, Massachusetts.
- Kiresuk TJ and Sherman RE. (1968) Goal attainment scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal* 4: 443-453.
- Lathouwers K, Moor D and Didden R. (2009) Access to and use of Internet by adolescents who have a physical disability: A comparative study. *Research in Developmental Disabilities*: 702-711.
- Law M, Baptiste S, Carswell A, et al. (1998) *Canadian Occupational Performance Measure*, Toronto, Canada: CAOT Publications, ACE.
- Nansen B, Chakraborty K, Gibbs L, et al. (2012) MYBus': youth's mobile health, wellbeing and digital inclusion. *Journal of Community Informatics* [online], 9(2).
- Newman L, Wood D, Raghavendra P, et al. (2010) The internet's potential to increase social networks for young Australians with disabilities. *40th National Conference of the Public Health Association of Australia*. Adelaide, Australia.
- Ostensjo S, Oien I and Fallang B. (2008) Goal-oriented rehabilitation of preschoolers with cerebral palsy--a multi-case study of combined use of the Canadian Occupational Performance Measure (COPM) and the Goal Attainment Scaling (GAS). *Developmental Neurorehabilitation* 11: 252-259.
- Palisano RJ, Rosenbaum P, Bartlett D, et al. (2008) Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology* 50: 744-750.
- Raghavendra P, Wood D, Newman L, et al. (2011) Effectiveness of internet solutions to facilitate social participation in youth with acquired brain injury. *Novita Community Paediatric Acquired Brain Injury Conference*, November; Adelaide, Australia.
- Raghavendra P, Olsson C, Sampson J, et al. (2012a). School participation and social networks of children with complex communication needs, physical disabilities and typically developing peers. *Augmentative and Alternative Communication* 28(1): 33-43.
- Raghavendra P, Wood D, Newman L, et al. (2012b) Why aren't you on Facebook?: Patterns and experiences of using the Internet among youth with physical disabilities. *Technology & Disability* 24: 149-162.
- Raghavendra P, Newman L, Grace, E, et al. (2013a). "I could never do that before": Effectiveness of a tailored Internet support intervention to increase the social participation of youth with disabilities. *Child: Care, Health & Development*. 39, 552-561.
- Raghavendra, P., Grace, E., Newman, L., et al. (2013b). "They think I'm really cool and nice": The impact of Internet support on the social networks and loneliness of young people with disabilities. *Telecommunication Journal of Australia*. **63 (2): 22.1-22.15.**
- RERC on Communication Enhancement (2011, March 14) . Mobile devices and communication apps: An AAC-RERC White Paper. Accessed 20 March 2013, Available from: <http://aac-rerc.psu.edu/index.php/pages/show/id/46>
- Stewart M, Barnfather A, Magill-Evans J, et al. (2011). Brief report: An online support intervention: Perceptions of adolescents with physical disabilities. *Journal of Adolescence* 34: 795-800.
- Schwartz S, Lowe S and Rhodes J (2012). Mentoring Relationships and Adolescent Self-Esteem. *The Prevention Researcher*. 19(2) 17 -20.
- Takahira M, Ando R and Sakamoto A. (2012) Children and the internet in Japan: Effects of internet use on learning and social adjustment. *Proceedings: Science of human development for restructuring the "gap widening society"* 17: 63 - 72.

- Thirumanickam A, Raghavendra P, Olsson C. (2011). Participation and social networks of school-age children with complex communication needs: A descriptive study. *Augmentative and Alternative Communication* 27: 195–204.
- Turner-Stokes L. (2009). Goal attainment scaling (GAS) in rehabilitation: a practical guide. *Clin Rehabil* 23: 362-370.
- Valkenburg P and Peter J. (2007) Adolescent's Identity Experiments on the Internet; Consequences for Social Competence and Self-Concept Unity. *Communication Research* 35: 208-231